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ADD Program Update

Administration on Developmental Disabilities

Administration for Children and Families • U.S. Department of Health and Human Services

Commissioner's Message

Family Support 360

ADD is making gains through Family Support 360. Our grantees are doing excellent work in systemic change, advocacy, capacity building, protecting human rights, providing training, conducting research, reaching out into the communities, keeping the public informed, and supporting the development of family-centric one-stop centers.

Family Support 360 exists as a means to design and implement a family-friendly human service system, using a one-stop approach, so that people with developmental disabilities and their family, may stay together and thrive. Consumers for this program are from historically unserved or underserved populations. The services that will be provided target the individual families needs.

One-stops are a single point to locate a spectrum of services, determine eligibility, plan, apply, confirm delivery, and maintain quality control.

The goals of Family Support 360 will be met through planning and implementation grants with support from State and local officials. Realistic outcomes are anticipated because the projects begin with a small number of families and expand as they gain success and support. Involving the families in the planning stage, tracking results, and replicating successes will ensure continued viability of the program.

In 2003, ADD awarded 31 planning grants. Currently, there are 14 UCEDDs, 5 Councils, and 12 other grantees working on Family Support 360 projects using funding from this grant program. Grantees are finding their plans and ideas are being well received by consumers. Grantees are building programs based on existing services and their availability, and are aiming to simplify the process for people with developmental disabilities and their families to locate and utilize what is available. The projects are integrating options available from government, non-

profit, and faith-based groups to compare strategies, streamline services, establish partnerships, eliminate redundancies, and build a community network. The grantees are identifying what their challenges will be. The challenges include marketing and outreach difficulties in large states, language barriers, cultural distinctions, targeting populations, finding a location for one-stop centers and creating the most accommodating and efficient space, and making all of it replicable.

One-stops will require ongoing self-evaluation to identify changing populations and their needs, identify gaps in services, recruit new partners, keep up with changing laws, and maintain or increase funding resources.

Family Support 360 is a small program with big expectations. In the future, what we learn from these projects will be used to transform the human service system to make it one that operates at the convenience of the consumers to give them what they need- where, when, and how they need it.

For information on Family Support 360 send an e-mail to pmorrissey@acf.hhs.gov.

Commissioner's New Freedom Spotlight Winners for Housing and Recreation

As a part of ADD commitment to grantee success, ADD is spotlighting the following programs that have shown ingenuity, innovation, dedication, or other exemplary efforts in their projects. Thank you to all grantees who submitted their projects for consideration. Keep up the good work!

Housing

Michigan DD Council

Project Name: Housing Accessibility, Affordability and Supports/Services

****Honorable Mention –***

Louisiana State University Health Sciences Center, Human Development Center (LSUHSC/HDC)

Project Name: Housing Initiatives Program

Recreation

Utah State University, Center for Persons with Disabilities

Project Name: Leisure and Recreation for Differently-abled Kids

****Honorable Mention – Michigan DD Council***

Project Name: Inclusive Recreation for Youth

The next New Freedom Spotlight categories are Education and Child Care. A new questionnaire and deadline for submission will be sent to each Executive Director soon. Submissions and questions may be sent to acfaddcomm@acf.hhs.gov.

Program Progress

Protection and Advocacy Agencies

Illinois

Victory in Tinder Case

Equip for Equality, the Protection and Advocacy Agency in the State of Illinois, has won a landmark court victory. On February 24, 2004 the Appellate Court reversed a previous decision in the case of B. J. Tinder v. Illinois Department of Public Aid and Jackie Garner, Director. B.J. Tinder has cerebral palsy, and previously resided in a Community Integrated Living Arrangement (CILA). CILA homes are part of an Illinois program for Medicaid eligible persons with developmental disabilities. Two years later, Mr. Tinder began the application process to return to a CILA home, after living in several settings that included a hospital and rehabilitation stay for medical reasons. The Illinois Department of Human Services rejected his applications on the grounds that Mr. Tinder was not developmentally disabled and would not benefit from active treatment.

Equip for Equality worked with Mr. Tinder to prove to the court that Mr. Tinder's disabilities were consistent with the definition of developmental disability provided under Illinois law. They also worked to prove that there was no "active treatment" requirement in the framework of the CILA program.

The court reversed the early decisions on the grounds that Mr. Tinder had been held to standards that could not be justified under the laws and program definitions as they were written. Victory in the Tinder case opens the door for other people with disabilities in Illinois who are seeking a community residential setting. The Tinder victory represents the end to a five-year struggle, and will give Mr. Tinder the opportunity to live in his least restrictive setting. For information on the Tinder case or Equip for Equality, send an e-mail to contactus@equipforequality.org

For information on other ADD P&A programs, contact Jacqueline Ezzell, jezzell@acf.hhs.gov.

State Councils on Developmental Disabilities

California

Ninety-one grandparents throughout California are better prepared for the challenges of raising infant/toddler grandchildren with special needs, thanks to the California Council funded Senior Moments Project. In response to state and federal identification of the needs of aging caregivers as a major issue, this project developed specialized trainings, on: Grandparents as Parents; Young Childrens' Social/Emotional Development; and How to Address Challenging Behaviors. To encourage participation, trainings were free of charge, and included childcare and the availability of transportation options. Trainings were provided in Fresno, Oakland, and Los Angeles, and have been videotaped to serve as a permanent training resource. Copies of the videotaped training series will be disseminated to California Family Resource Centers, grandparent support groups, and all California Regional Centers.

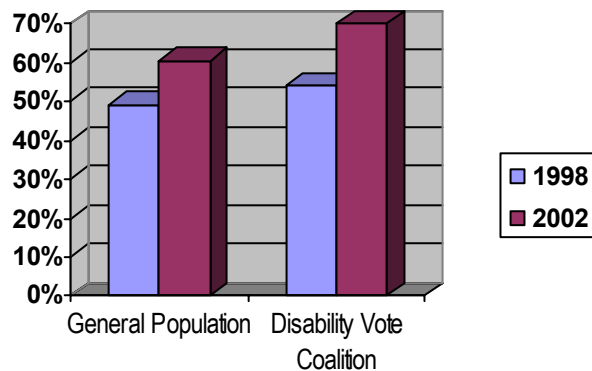
Missouri

Get Out The Vote

The Missouri Planning Council for Developmental Disabilities worked with the Missouri Disability Vote Project to:

- assess and increase voter registration
- assess and increase level of political participation

Over 80 organizations were contacted to participate in the Get-Out-The-Vote (GOTV) campaign and 19 agreed and became the MO Disability Vote Coalition. The MO Citizen Education Fund provided a grant to pay for a list enhancement for any and all disability organizations that wished to participate. When the 19 organizations pooled their contact lists, we had over 48,000 complete records. Over 21,000 calls were made and 8,500 direct mailings were sent to members of this list for the 2002 election cycle. The project attracted the attention of the Gill Foundation, a national foundation



committed to funding nonpartisan, capacity-building efforts at the state level and another free list enhancement was provided in the summer of 2003. All organizations in the coalition showed a substantial increase in voter turnout from that of the last off-year election cycle in 1998.

The intent of the telephone contacts was to remind individuals of the upcoming election and encourage them to vote. Calls were strictly nonpartisan and information about how to vote was not shared even if requested. During the phone conversations, if individuals were identified who

had not registered, they were asked if they would like to register and the callers sent them information or told them where to go to register. If transportation to the polls was identified as an issue that was preventing individuals from voting, the callers shared resources to assist them in getting to the polls and also informed them about how to get on the permanently disabled voter list with their local election authority.

Statewide voting among coalition members was increased by 16% or 3,517 of those contacted, voted. Also, 2,837 new voters registered as a result of the GOTV effort.

For information on ADD State Council programs, contact Mary Beth Greene, mgreene@acf.hhs.gov

University Centers for Excellence in Developmental Disabilities Education, Research and Services

Delaware

Advocacy Awareness Project for People with Disabilities and their Families

The need for more representation by self-advocates and families within the state's budgetary process prompted the University of Delaware's Center for Disabilities Studies, in conjunction with a self-advocate and volunteer, to develop *Advocacy Works*. *Advocacy Works* is a pilot project that recruited and supported individuals and their family members, so they were able to testify at Delaware's annual Joint Finance Committee (JFC) hearings about the budgets of the State Department of Health and Social Services.

The JFC is a legislative committee made up of six Representatives and six Senators that are responsible for approving the Governor's recommended budget for each state fiscal year. State agency directors, advocates, and other interested individuals are given an opportunity to testify and request changes to the budget as well as suggest new services that could meet unmet needs. Historically, few self-advocates have testified at these hearings. Many advocates have commented that they felt intimidated by the hearing process or have had difficulty obtaining the physical supports needed to attend the hearings.

The project's process involved several steps in order for self-advocates and family members to testify. A letter was sent to Partners in Policymaking graduates of the past ten years, as well as advocacy groups such as the Arc of Delaware and the Mental Health Association of Delaware. Because many people had expressed concern that explaining negative scenarios to legislators could result in a loss of services, the *Advocacy Works* information included helpful hints and guidelines for people in preparing testimony. The need for people to share their own positive *and* negative experiences during the budget hearings so that legislators can make truly informed decisions was stressed. Finally, the importance of a cross disability approach was highlighted. This provided a unified front, which demonstrated that systemic change is needed for all people in Delaware. Subsequent steps in the process provided support in coordinating transportation, drafting testimony, and the actual testifying process.

Out of 260 recipients of the *Advocacy Works* letter and information, thirteen individuals testified, all Partners in Policymaking graduates. Seven of these individuals testified for the first time. In addition, fifteen people called or emailed to inquire with questions about the letter and the general process, and many people requested to be included in any awareness activities for next year's hearings. Testimony by people with disabilities and family members was given on a range of topics including: respite care, community-based alternatives, caregiver supports, personal control of support services, services for individuals with traumatic brain injury, and others.

Maryland

Early Intervention for Infants and Toddlers and Their Families in the Jewish Community

The Kennedy Krieger Institute Department for Family Support Services, the Baltimore Infants and Toddlers Program, the Baltimore county Infants and Toddlers Program, and the Center for Jewish Education are partnering to provide outreach, training, and service in the Baltimore Jewish community through *Kodem Kol*, a program for infants and toddlers who are eligible for early intervention services and their families.

To assist families in focusing on a child's developmental needs and capitalizing on his or her natural ability to learn, Baltimore Infants and Toddlers Program has a family-centered system of early intervention services for young children who may be experiencing a delay in development or who have a diagnosed condition that has a high probability of delay and their families. An early intervention service coordinator from the Jewish community provides assistance to families at the Kennedy Krieger Institute to secure early intervention services in areas that the child's family identifies as priorities and concerns. These services may include:

- Family education, counseling, and support
- Special instruction
- Speech pathology and audiology
- Occupational therapy
- Physical therapy
- Psychological services
- Medical services for diagnosis
- Health services related to other early intervention services
- Other services may be available as appropriate

Referrals are made to the Baltimore or Baltimore County Infants and Toddlers Programs then the families are referred to the *Kodem Kol* service coordinator. The coordinator contacts the family to arrange a home visit and to schedule an eligibility evaluation. If the infant or toddler is eligible, the coordinator and the family develop the Individual Family Service Plan; then services may begin in the home or other natural environment. Services are monitored by the family and the coordinator. At the age of 30 months transition plans are begun, either to Part B services of IDEA or to other appropriate community services.

Missouri

Sharing Our Strengths

Sharing Our Strengths (SOS) is a project of the University of Missouri – Kansas City Institute for Human Development (UCE) that provides peer support matching based on the parent to parent model of support. Originally a part of an ADD funded Consumer and Family Directed Support program, *SOS* is now funded by the Missouri Planning Council for Developmental Disabilities. Parents and family

members of children newly diagnosed with a developmental disability are matched with more experienced families in similar situations. Self advocates and professionals can also be matched with a peer mentor.

The following is a true story of one parent who was matched with a mentor through the *SOS* program.

S's story begins in February, 2002. She was a happy wife and mother of two little boys and expecting a third son in a few weeks. But something felt different, and after talking to her doctor, an ultrasound was performed. She was shocked to find out that her instincts were correct – her baby had a condition called agenesis of the corpus callosum (ACC). This is a rare congenital disorder in which the structure that connects the two hemispheres of the brain is either partially or totally absent. Children with the most severe form of ACC may have cognitive disabilities, seizures, hydrocephalus, and spasticity. There is no standard treatment for ACC, but treatment usually involves management of symptoms and seizures if they occur. S's baby had hydrocephalus (fluid on the brain). The increased fluid was causing increased pressure on her baby's brain. Two weeks after she first contacted the doctor with her concerns, her baby boy was delivered. The infant required several surgeries after birth and the following year. He also began having seizures.

The mother contacted *Sharing Our Strengths (SOS)*. She was mainly seeking emotional support and reported that she felt lost. She was looking for someone to talk to about her frustrations, as well as good days. She was matched with an *SOS* mentor in her region. *SOS* mentors attend orientation which includes training on topics including the role of the mentor, communication and listening skills, coping and adjustment, and the problem solving process. Mentors volunteer to be matched to another person based on needs, shared interests, and challenges. Mentors share their own experiences, practical information, resources and offer emotional support. S's mentor also has a son, but her son has cerebral palsy, seizures and asthma. Even though the two families did not share the same diagnosis, there were many similarities in the two children's conditions.

The mentor contacted S by telephone at first, and later the two exchanged email correspondence. They eventually met in person. During the time of the match, S's son was hospitalized several times. The new mother stated later that she couldn't have made it through the frequent hospitalizations without her mentor.

When asked what was the best part of the *SOS* match experience, S replied that it was the chance to talk to someone or express whatever frustration she was feeling, and be understood and not judged. She also said, "It was being able to talk to someone who would just listen and then when I finally got through venting, I knew they could relate. It was kind of like having a big sister I could turn to when I needed to." She also talked about how family and friends often didn't understand that every little frustration as well as every little accomplishment could be a big deal.

S expressed that she was very happy with her mentor, and with the *SOS* experience. She says, "I knew after one call from my new friend that *SOS* would help me through the hard times. My *SOS* contact is there for every hospital stay via phone or email. She is there, full of encouragement, on the days I want to cry. She has helped me find books, websites, and other support groups related to my son's health. What means the most to me is that I know that she has been in the same spot I am in. My *SOS* friend has helped me through 14 surgeries, numerous hospital stays, and how to deal with rude people when they ask questions about my child. Thank you *SOS*!"

New Hampshire

Sustained Family Support: *Project LEAD* at UNH

Family supports should not end just because funding does. Finding innovative ways to continue the hard work and outreach that results from a grant-funded project can be challenging, but the Institute on Disability/UCED at the University of New Hampshire is dedicated to sustaining grant-funded work.

Project LEAD (Learn, Empower, Advocate, and Determine) – an ADD-funded person-centered-planning training and technical assistance grant which ends in June – is just one example of how the Institute on Disability works to sustain supports for families, individuals with disabilities, and others invested in community inclusion.

Project LEAD is creating a new organization called *Innovative Facilitators (I.F.)* that will continue the project's efforts to provide person-centered planning training to self-advocates, families, practitioners and personal support teams.

A national five-day training series on Methods, Models and Tools for Person-Centered Planning will kick off *I.F.* in August. During the first year, *I.F.* will: provide curriculum materials and training about person-centered planning; establish a facilitator's network; offer support regarding the mentoring process; and provide technical assistance.

A specialized parent series, *SPECS: Specific Planning Encourages Creative Solutions*, will also be provided to serve as an educational series for parents and family members who take the lead in providing day-to-day supports. Sessions include planning orientation, hands-on practice with specific tools, experiential (or action) learning, how to design supports, and financing creative solutions.

“What is unique about *I.F.*,” Cotton says, “is that the organization and its curriculum draws directly from *Project LEAD*'s work and supports an existing group – families, individuals with disabilities, practitioners, self-advocates and others.”

For more information about *Project LEAD* or *I.F.*, contact Patty Cotton at (603) 862-0284 or visit the Institute on Disability's Web site at www.iod.unh.edu.

Vermont

Center on Disability and Community Inclusion (CDCI)

CDCI and the Vermont Department of Education collaboratively developed a model of family support known as the *I-Team*. Our main focus is to support children with multiple disabilities, their families, and their school teams. We refer to our family support advocates as Family Resources Consultants (FRCs). In collaboration with educational consultants and related services consultants on the *I-Team*, the Family Resources Consultants make connections directly with the families of the children. They provide information about the special education process, resources on disabilities, and community programs. They attend school meetings with families as requested, staying as connected as the families choose. Because of the unique interdisciplinary nature of the *I-Team*, the entire school team, including the family, is strengthened and supported.

For information on this project contact: Michaela Collins, Center on Disability & Community Inclusion, University of Vermont, Michaela.Collins@uvm.edu.

For more information on UCEDD programs contact Jennifer Johnson, jjohnson1@acf.hhs.gov.

Projects of National Significance

Institute for Community Inclusion- UMASS

The *Family Support Net Project*, is a three year Project of National Significance funded by ADD. The goal of the *Family SupportNet Project*, is to teach individuals with disabilities and families of diverse cultural, linguistic, and ethnic communities how to access internet resources to enhance the quality of their lives. The following stories, exemplifying the project, first appeared in *Family SupportNet's* online newsletter.

E.M. is a mother, a person with mental retardation and physical limitations, and a budding children's story writer. She used her newly acquired internet skills to reconnect with her teenage son and extended family via email. She also writes out her stories to share with others, and communicates with an e-Buddy through the Best Buddies email program. She regularly emails the project instructor, as well as many others with updates about her life. She often speaks about how much the computer has changed her life for the better. She is progressing in her writing hobby because she finds typing out her stories enjoyable, productive, and fun to send to her loved ones.

Another success story comes from the "J" family. The father, mother and son all took *Family SupportNet Project* computer lessons at the same time. Mr. J. used his skill to take college courses for the first time in his life. Mrs. J. used her skills to communicate with service providers and look up all types of resources for her son, as well as write fundraising cookbooks for her community. Their son writes emails to an e-Buddy, and he and his mother enjoy creating sports books with information they collect from online articles. He proudly shows off his "Sports Facts" books to everyone he meets.

For more information on this project contact: Meredith Aalto, meredith.aalto@umb.edu

For information on Projects of National Significance contact April Myers, amyers@acf.hhs.gov

Upcoming Events & Announcements

Announcements

Reminder: ADD's New Office Space

In early January, ADD completed their move to the fourth floor of the Hubert H. Humphrey Building, at the Department of Health and Human Services. ADD's address remains unchanged with the exception of the mail stop. For reference our mailing address is:

ADD/ACF/HHS

Mail Stop: **HHH 405 D**

370 L'Enfant Promenade

Washington, DC 20447

All staff members can be reached at their previous phone numbers. The new ADD fax numbers are 202-205-8037 and 202-690-6904. Your intended recipient will be able to tell you which is most convenient to their space.

CMS Announcement: Prescription Drug Discount Cards

Medicare-approved Prescription Drug Discount Cards are available to people who receive Medicare, including some people with disabilities, who meet specific income and other qualifications. The Centers for Medicare and Medicaid Services is attempting to ensure that people who are eligible for Drug Discount Cards and their advocates have access to information about the program. Efforts to ensure that information about the Drug Discount Card is accessible and usable by all consumers include web-sites that meet 508 requirements and publications in a variety of languages and alternative formats such as large print and Braille. CMS is also emphasizing the importance that publications are written in consumer-usable language

Further information on the Drug Discount Card program can be obtained by calling 1-800-MEDICARE (1-800-633-4227) and asking about "drug savings." TTY users should call 1-877-486-2048. Information can also be found at www.medicare.gov on the web. Viewers of this website should select "Prescription Drug and Other Assistance Programs."

Upcoming Events

Women's Health Week

The U.S. Department of Health and Human Services will celebrate National Women's Health Week, May 9-15, 2004. The signature event, National Women's Check-Up Day, will be May 10, 2004. For more information go to <http://www.4woman.gov/whw>.

Access for All

June 14 - 15, 2004 - Access for All: Building, Funding and Improving Community Transportation
Access for All is being sponsored by the Community Transportation Association of

America (CTAA) and the University of New Hampshire Institute on Disability (UCEDD). This two-day conference, which will focus on building, funding and improving community transportation, will provide information on what you can do to further expand transportation services in your community. Special emphasis will be placed on expanding transportation options for persons with disabilities. The conference will occur at the Washington State Convention and Trade Center in Seattle, WA. For registration, agenda and available scholarships, visit: <http://www.ctaa.org/expo/2004/accessforall.asp>.

Training Opportunity

June 23-27, 2004 - Training Institutes 2004: Funded and organized by the National Technical Assistance Center for Children's Mental Health at the Georgetown University Center for Child and Human Development (DC UCEDD) in partnership with the Child, Adolescent and Family Branch of the federal Center for Mental Health Services, Substance Abuse and Mental Health Services Administration. Georgetown University is offering Training Institutes on local systems of care for children and adolescents with or at risk for emotional disturbances and their families. The intent of the Institutes is to provide in-depth, practical information on how to develop and sustain systems of care and how to provide high quality, effective clinical interventions within them. The event is taking place in San Francisco, CA. Registration information is located at: <http://gucchd.georgetown.edu/institutes.html>.

Youth Conference

July 24-27, 2004- NYLN Conference: The National Leadership Conference for Youth with Disabilities will be held in Washington, DC. The theme for the Conference is Learning, Living, Leading: Youth with Disabilities Continuing the Legacy. Participants will have exciting opportunities to learn from national disability leaders, public officials, and other young leaders with disabilities from all over the country. Conference goals include helping prepare the next generation of disability leaders and identifying ways to improve policies and supports for young people with disabilities. Most will be between the ages of 18 and 24, however a small number of youth that are 16 or 17 years old will be chosen as "Emerging Leaders." Details at NYLN web site: <http://www.nyln.org>